Racial Differences in Medical Mistrust among Men Diagnosed with Prostate Cancer

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Abstract

Purpose—Mistrust of health care providers and systems is a significant barrier to quality health care. However, limited empirical data are available on perceptions of medical mistrust among individuals diagnosed with cancer. The purpose of this study was to identify sociodemographic, clinical, and cultural determinants of mistrust among men diagnosed with prostate cancer.

Patients and Methods—We conducted an observational study among 196 African American (n=71) and white (n=125) men who were newly diagnosed with prostate cancer during 2003 through 2007.

Results—Race, education, health care experiences, and cultural factors had significant effects on mistrust. African American men (p=0.01) and those with fewer years of formal education (p=0.001) reported significantly greater levels of mistrust compared to white men and those with greater education. Mistrust was also greater among men who had been seeing their health care provider for a longer period (p=0.01) and those with lower perceptions of interdependence (p=0.01).

Conclusions—Our findings suggest that efforts to enhance trust among men diagnosed with prostate cancer should target African American men, those with fewer socioeconomic resources, and men with lower perceptions of interdependence. Reasons for deterioration in trust associated with greater experience with specialty providers should be explored along with the effects of interventions that are designed to address the concerns of individuals with greater mistrust.

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INTRODUCTION

Being diagnosed with cancer is an acute medical crisis (1); effective communication between patients and physicians is critical to ensuring that men understand their diagnosis, options for treatment, and the pros and cons of each treatment option. However, lack of trust in health care providers and the medical system is a significant barrier to effective communication and use of clinical services (2) and may also contribute to racial differences in outcomes following prostate cancer diagnosis (3). Trust is a multi-dimensional construct that reflects patient's expectations that health care providers will behave in ways that demonstrate that their interests are a priority (4-6). Key components of trust include perceptions of the health care provider's interpersonal skills and technical abilities, suspicion of health care systems and providers, expectations of unfair treatment, and perceived support from providers (4,5,7,8). Trust is influenced by race and health care experiences; African Americans and individuals with less experience with providers are most likely to report low levels of trust (9-11). Fewer quality interactions with providers are also associated with low trust (9,12). Recent research has also shown that African American men diagnosed with prostate cancer report lower levels of trust compared to white men (3); however, empirical data are not available on predictors of mistrust in men diagnosed with this disease.

The purpose of the present study was to identify factors having significant independent associations with mistrust among African American and white men who were diagnosed with prostate cancer. Because of the marked racial disparities in prostate cancer outcomes and consistent racial differences in trust (3,9,10,13), mistrust that is rooted in one's racial experience and perception was of particular interest in this study. We predicted that African American men would report significantly greater levels of mistrust compared to white men. To understand the context within which mistrust is manifested, we also evaluated the relationship between mistrust and health care experiences (e.g., length of the patient-provider relationship) and cultural factors. We hypothesized that mistrust would be associated with having a shorter relationship with health care providers. Culture is defined as a set of shared and socially transmitted ideas about the world that are passed down from generation to generation (refs); previous research has shown that beliefs and values related to religiosity are associated with trust in minorities (14). However, it is unknown if these factors are associated with mistrust among ethnically diverse samples of men facing an acute clinical diagnosis. Further, while previous research has demonstrated that cultural values related to collectivism are associated with aspects of the patient-provider relationship that contribute to trust (15), endorsement of these values may also have a direct effect on mistrust. That is, since collectivism reflects the extent to which interdependence, relationships, and cooperation with others is valued (16); and mistrust is an indication of the quality of the relationship between providers and patients, mistrust should be greater among men with lower levels of collectivism. On the other hand, individuals with greater religiosity may be more inclined to mistrust health care providers and systems because of a greater reliance on their spiritual faith and practices. A better understanding of mistrust among men newly diagnosed with prostate cancer is needed to identify patient and system factors that should be addressed to enhance trust among African American men with the goal of improving their treatment trajectory in terms of decisions and outcomes.

METHODS

Study Population

This study was conducted at the University of Pennsylvania and was approved by the Institutional Review Board. Subjects were African American and white men who were newly diagnosed with prostate cancer. To be eligible for participation, men had to be

diagnosed with a biopsy-confirmed case of prostate cancer (stage T1 through T3) within the past two to five months and men had to have complete clinical data on stage, PSA, and Gleason score for inclusion in the analysis. Consistent with prior research in newly diagnosed cancer patients (17), the study enrollment rate was 46% among all eligible men who were referred to the study (n=470). There were no differences in study enrollment based on Gleason score (χ^2=0.05, p=0.83) or stage (χ^2=0.43, p=0.51)[1]; however, white men (χ^2=8.61 p=0.003) and those who had lower a PSA (t=2.64, p=0.01) were most likely to enroll in the study. Among men who enrolled in the study, 92% completed the baseline telephone interview.

Procedures—Eligible subjects were recruited into the study at urology and radiation oncology practices located in the Philadelphia, PA metropolitan area. Recruitment sites included the urology practices at the University of Pennsylvania Health System (UPHS) and community-based urology practices. Men were recruited into the study by clinic and research staff during a follow-up appointment after they had been informed about their biopsy result. It should be noted that some men recruited at the UPHS were identified at the pre-surgery class for radical prostatectomy and others were being seen for a second opinion and/or treatment. At each recruitment site, eligible men received a verbal and written description of the study and the procedures involved in participation. Written informed consent was obtained from all men who enrolled in the study. Men were contacted for a baseline telephone interview about one to four weeks following study enrollment and provision of written informed consent. The baseline was completed by trained research assistants at the University of Pennsylvania and took about 30-minutes to complete. The baseline was a structured survey that obtained sociodemographics, race and treatment status and assessed cultural factors and mistrust. Men were contacted for follow-up telephone interviews at 3-, 6-, and 12-months after the baseline. The present study focuses on data collected during the baseline telephone interview.

Measures

Sociodemographics: Race, age, marital status, education, income, and employment status were obtained by self-report during the baseline telephone interview. With the exception of age, these variables were re-coded into dichotomous variables based on the distribution of responses.

Clinical Factors: PSA, Gleason score, and TNM stage at diagnosis were obtained at enrollment. With the exception of PSA, these items were re-coded into dichotomous variables (e.g., stage T1 versus T2/T3) based on the distribution of responses. Treatment status was obtained by self-report during the baseline telephone interview by items that asked men if they had received surgical, radiation, or expectant (e.g., watchful waiting) treatment. Men who had completed surgical treatment or had initiated radiation or other types of therapy (e.g., cryosurgery) were categorized as having initiated or completed treatment. Men who had not initiated any treatment were categorized as being pending for treatment.

Health Care Experiences: As in prior research (9), health care experiences were evaluated in terms of the length of the relationship with the physician at each recruitment site. Specifically, men were asked to report how long they had been seeing the physician who was providing their prostate cancer care. This variable was re-coded into a dichotomous variable (> three months versus < three months) based on the distribution of responses.

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[1]Fifty men who declined study enrollment were missing information on stage.

Cultural Factors: We used the religiosity and collectivism scales developed by Lukwago and colleagues (18) to evaluate the extent to which men endorsed religious values (e.g., when I am ill I pray for healing; I have a personal relationship with God) and those related to group interdependence and support (e.g., it is important for families to do everything they can to help others move ahead in life). The religiosity scale included 9 Likert-style items and the collectivism scale had 6 Likert-style questions. These scales had acceptable internal consistency in our sample (Cronbach's alpha for collectivism=0.64 and religiosity=0.94); higher scores indicated greater levels of collectivism and religiosity.

Mistrust: We used the Group-Based Medical Mistrust Scale (GBMMS) (8) to evaluate mistrust in health care providers and systems. The GBMMS is a 12-item Likert-style scale that measures suspicion of health care providers and the health care system, expectations about racial discrimination by health care providers, and perceived support from providers. The GBMMS has been validated in samples that included African American and Hispanic women (8) and has also been administered to men and women in primary care and emergency department settings as part of research on treatment for migraines and adherence to colon cancer screening, respectively (19,20). The GBMMS had good face validity with validated measures of trust (6) and had good internal consistency in this sample (Cronbach's alpha=0.86). Higher scores indicated greater mistrust.

Data Analysis

Descriptive statistics were generated to characterize subjects in terms of sociodemographics and clinical characteristics. We then used chi square tests of association and t-tests to identify racial differences in sociodemographics and clinical factors. Next, we conducted bivariate analyses to evaluate the relationship between mistrust and sociodemographic, clinical, and cultural factors. These analyses were performed to identify variables for inclusion in the regression model of mistrust. We then used regression analysis to identify factors having significant independent associations with mistrust. Because of the potential for confounding within recruitment sites, we evaluated the effects of these factors on mistrust using fixed effects modeling. Recruitment site was treated as a fixed effect to control for clustering within site. Variables that had a bivariate association of $p<0.10$ with mistrust were included in the model. Since race was associated significantly with sociodemographic and cultural factors in our previous research (21), we included interaction terms in the model to determine if the effects of these factors were different for African American and white men.

RESULTS

Table 1 shows the sample characteristics. There were no racial differences in age (t=0.07, p=0.95), employment status (χ^2=2.87, p=0.09), Gleason score (χ^2=1.40, p=0.24), stage (χ^2=3.04, p=0.08), or length of care (χ^2=2.41, p=0.12). However, white men reported significantly greater incomes (χ^2=12.57, p=0.0004) and education (χ^2=16.86, p=0.0001) and were more likely to be married (χ^2=11.17, p=0.001). White men were also more likely than African American men to have initiated or completed treatment (χ^2=7.63, p=0.01). African American men had higher PSA levels compared to white men (t=2.97, p=0.004).

Table 2 shows the bivariate analysis of mistrust. Of the sociodemographic characteristics, race, education, and income were associated significantly with mistrust. Compared to white men, African American men reported significantly greater mistrust. In addition, men who were high school graduates or had less education and those with incomes less than $50,000 were most likely to report greater mistrust. Being unmarried had a marginally significant association with greater mistrust. With respect to clinical factors, length of care and treatment status were associated significantly with mistrust. Men who had been seeing their

health care provider for more than three months reported greater mistrust compared to those with a shorter length of care. Compared to men who had completed or initiated treatment, those whose treatment was pending also reported significantly greater mistrust. In terms of cultural factors, both collectivism and religiosity were associated significantly with mistrust. Men with lower perceptions of interdependence and those with greater religiosity reported higher levels of mistrust.

The multivariate model of mistrust is provided in Table 3. There were significant main effects for race, education, marital status, length of care, and collectivism. Specifically, African American men, men who had a high school education or less, and those who had been seeing their health care provider for more than three months reported significantly greater levels of mistrust compared to white men, those with greater education, and men with a shorter length of care. In addition, lower levels of collectivism were associated significantly with greater mistrust. The only significant interaction was between race and marital status (Estimate=-6.43, SE=2.30, p=0.006). Marital status had a significant effect on mistrust among white men; mistrust was greater among men who were married (Estimate=3.68, SE=1.72, p=0.03). Other interactions were not significant (p>0.15). The sample size was sufficient for detecting significant interactions as reflected in the confidence intervals for these non-significant interactions, which were shorter than that of the interaction that was statistically significant (22).

DISCUSSION

To our knowledge, this is the first empirical study to evaluate perceptions of medical mistrust among men who are newly diagnosed with prostate cancer based on sociodemographics, health care experiences, and cultural factors. Consistent with previous research (9,10), we found that African American men and those with fewer years of formal education reported significantly greater mistrust compared to white men and those with more education. Racial differences in mistrust may reflect differences in the quality of interactions with health care providers in oncology settings (12,23); however, other factors may influence mistrust among white men. We found that marital status had a significant effect among white men; mistrust was greater among those who were married. Spouses and live in partners are an important source of support for men who are diagnosed with prostate cancer; and the presence or absence of spouses at consultations also has implications for men's engagement with health care systems (24,25). It could be that spouses have less of an effect on mistrust among African American men because their perceptions of health care providers and systems are based on their own negative experiences. Attempts to replicate the present findings would do well to examine whether the spouse at consultations with providers contributes to an explanation of the complex effects of marital status on trust.

In contrast to our hypothesis and previous research (11), we found that mistrust was significantly greater among men who had been seeing their health care provider for a longer time period. One reason why our finding differs from those reported in previous research because the present study was conducted with men who were seeing a specialist physician in an oncology setting, whereas most prior studies on trust have been conducted in primary care settings (6,11). It may be that with repeated interactions, men accumulate disappointments in terms of their provider listening to them, providing information that they can understand, and having their concerns addressed. This possibility could be readily examined in future research and is important area to explore in order to reduce racial disparities in prostate cancer outcomes.

The results of the present study demonstrate that race and health care experiences are not the only determinants of mistrust among men diagnosed with prostate cancer. We found that

collectivism had a significant effect on mistrust; as collectivism decreased, mistrust increased. Collectivism is a cultural factor that reflects the extent to which interdependence, cooperation, and relationships with others are valued; individuals with lower levels of collectivism may place greater importance on autonomy, independence, and self-direction (16). Previous research has shown that greater self-direction is negatively associated with trust in institutions such as health care systems (26); it could be that men with lower levels of collectivism are more skeptical about the health care system and whether or not providers act in their best interest. Alternatively, men with lower collectivism may have communication styles and preferences that are unsupported during clinical encounters. Previous research has shown that individuals who value autonomy and independence are likely to have a direct and open communication style (27), are willing to be assertive during interactions with health care providers (15), and expect positive responses from these efforts (15). However, Street and colleagues (28) found that only 16% of physicians prompted patient's participation during the clinical encounter through supportive talk or partnership building communication.

While this study provides novel information on predictors of medical mistrust among prostate cancer patients, some limitations should be noted. First, only about 50% of men enrolled in the study and it is possible that men with greater distrust were likely to decline study enrollment. However, our enrollment rates are similar to those reported in other research within newly diagnosed cancer patients (17) and more than 90% of men who enrolled in the study completed the baseline telephone interview. Thus, it is not likely that distrust is a barrier to completing study procedures. It should also be noted that in contrast to previous prostate cancer research (29,30), African American men made up a substantial proportion of the subjects in the present study. The observational nature of our study is an additional limitation that prevents us from establishing causality with respect to mistrust, health care experiences, and cultural factors. It is also possible that evaluating mistrust shortly after being diagnosed with prostate cancer may influence men's responses because they are reluctant to report perceptions of unfair treatment, suspicion, and lack of support when actively seeking medical care for an acute illness. However, similar methods have been used to evaluate trust in health care providers in other research with cancer patients (12). It is also important to acknowledge that we did not evaluate whether or not mistrust differs depending on racial concordance with providers. This is an important area for future research on mistrust in oncology settings. Studies should also examine the relationship between racial differences in mistrust and adherence to treatment recommendations among prostate cancer patients.

Despite these potential limitations, our results have important implications for strategies to enhance trust among individuals facing an acute medical crisis. Trust is a reflection of the quality of the patient-provider relationship; previous research has suggested that efforts to improve trust should focus on enhancing the provider's communication and partnership building skills (9,12). Our finding that mistrust was greater among men who had a longer relationship with providers further supports these recommendations. However, there is limited evidence that such efforts increase trust among patients (31). Since communication between patients and providers is a reciprocal process (32), it may be important to direct strategies for enhancing trust to individuals at increased risk for mistrust in addition to developing strategies that improve physician behaviors. Recent research has shown that health care providers and African American patients show less positive affect (e.g., responsiveness, engagement, assertiveness, and attentiveness) during clinical encounters (33) and about one-fourth of low-income men diagnosed with prostate cancer reported low self-efficacy to communicate with health care providers (1). Poor communication with providers had a significant effect on trust among lung cancer patients, especially those who were African American (12). Thus, it may be important to enhance the communication skills

of African American men and those with fewer socioeconomic resources (e.g., low education) to mitigate the patient's negative perceptions of providers and health care systems. Previous research has shown that communication skills training that consists of consultation planning for breast cancer treatment (e.g., identification and organization of questions, role playing questions) reduced communication barriers with oncologists and also increased satisfaction with communication among health care providers (34). In other research, community-based communication skills training that focused on enhancing assertiveness increased participant's confidence in their ability to communicate with health care providers (35). Communication skills training that help African American men and those with fewer socioeconomic resources to identify and organize questions about their diagnosis and treatment may also be effective at reducing suspicion of health care providers. Our findings also suggest that within these approaches, it may be important to consider men's communication preferences that are shaped by cultural factors. Future studies should also evaluate the effects of these interventions among men with different sociodemographic profiles.

Acknowledgments

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Table 1

Sample Characteristics (n=196)

Variable	Level	Total Sample n (%)	African American n (%)	White n (%)	Chi Square
Race	African American	71 (36%)			
	White	125 (64%)			
Marital status	Married	155 (79%)	47 (66%)	108 (86%)	11.17**
	Not married	41 (21%)	24 (34%)	17 (14%)	
Education level	≥ Some college	125 (64%)	32 (45%)	93 (74%)	16.86***
	≤ High school	71 (36%)	39 (55%)	32 (26%)	
Employment status	Employed	93 (47%)	28 (39%)	65 (52%)	2.87†
	Not employed	103 (53%)	43 (61%)	60 (48%)	
Income level‡	> $50,000	112 (57%)	29 (41%)	83 (67%)	12.57***
	< $50,000	83 (43%)	42 (59%)	41 (33%)	
Insurance status	Yes	192 (98%)	67 (94%)	125 (100%)	7.29**
	No	4 (2%)	4 (6%)		
Length of care	> 3 months	96 (49%)	40 (56%)	56 (45%)	2.41
	< 3 months	100 (51%)	31 (44%)	69 (55%)	
TNM stage	T2/T3	62 (32%)	17 (24%)	45 (36%)	3.04†
	T1	134 (68%)	54 (76%)	80 (64%)	
Gleason score	> 6	83 (42%)	34 (48%)	49 (39%)	1.40
	≤ 6	113 (58%)	37 (52%)	76 (61%)	
Treatment†† status	Initiated/Completed	111 (57%)	31 (44%)	80 (64%)	7.63**
	Pending	85 (43%)	40 (56%)	45 (36%)	
Age	Mean (SD)	63.6 (8.0)	63.6 (8.8)	63.6 (7.6)	T=0.07
PSA	Mean (SD)	6.4 (4.9)	7.99 (6.5)	5.50 (3.4)	T=3.00**

*** p<0.001

** p<0.01

* p<0.05

† p<0.10

‡ One participant was missing data for income.

†† Of the men who had initiated or completed treatment, 78 (70%) had a radical prostatectomy, 15 (14%) had radiation, 10 (9%) had hormonal therapy, 2 (1.8%) had brachytherapy, and 6 (7.2%) had multiple types of treatment

Table 2

Bivariate Analysis of Medical Mistrust

Variable	Level	Mean (SD)	P-value
Race	African American White	26.3 (7.0) 21.1 (5.9)	0.0001
Marital status	Married Not married	22.5 (6.7) 24.6 (6.8)	0.08
Education level	≥ Some college ≤ High school	21.2 (6.2) 26.1 (6.7)	0.0001
Employment status	Employed Not employed	22.2 (6.8) 23.6 (6.7)	0.14
Income level	> $50,000 < $50,000	21.7 (6.1) 24.7 (7.3)	0.002
Length of care	> 3 months < 3 months	24.2 (6.8) 21.7 (6.6)	0.01
TNM stage	T2/T3 T1	22.4 (7.2) 23.2 (6.6)	0.48
Gleason score	> 6 ≤ 6	22.6 (6.8) 23.2 (6.8)	0.56
Treatment status	Initiated/Completed Pending	22.0 (6.7) 24.4 (6.8)	0.03
Age	r = 0.10		0.16
PSA	r = 0.06		0.37
Collectivism	r = -0.16		0.03
Religiosity	r = 0.21		0.003

[***] $p < 0.001$

[**] $p < 0.01$

[*] $p < 0.05$

[†] $p < 0.10$

Table 3

Multivariate Model of Medical Mistrust[‡]

Variable	Level	Estimate	Standard Error
Race	African American White (Reference)	3.86[**]	1.36
Education	≥ Some college ≤ High school (Reference)	-3.82[***]	1.08
Marital status	Married Not married (Reference)	0.29	1.24
Income	> $50,000 < $50,000 (Reference)	0.39	1.13
Length of care	> 3 months < 3 months (Reference)	2.51[**]	0.95
Treatment status	Initiated/Completed Pending (Reference)	-0.87	1.08
Collectivism	§§§	-0.64[**]	0.25
Religiosity	§§§	0.09	0.07

Recruitment site did not have a significant effect on mistrust p=0.62

[‡]Model with main effects.

§§§Entered as a continuous variable.

[***]
  p<0.001

[**]
  p<0.01

[*]
 p<0.05

[†]p<0.10